

**Maine Newborn Hearing Program  
Advisory Board**

**Date: June 4, 2007**

**12:00 to 4:00**

**Members Present: Dr. Romy Spitz, Karen Hopkins, Eileen Peterson, Kristen Shorey, and Louise Packness**

**Program Staff: Betsy Glencross, Katie Blanchard**

**Interpreters: Mary Jane Grant, Carol DeStefano**

**Guest: Lisa Glidden**

**Members Absent: Corinne Chipmann, Dr. Brenda Medlin, Michelle Markie, Richard Aronson, Julia Bell, Carrie Ouellette**

**Moderator: Betsy Glencross**

**Scribe: Eileen Peterson & Katie Blanchard**

**I. Approval of minutes from: June 4, 2007, accepted.**

**II. Program Updates**

- **MNHP – Betsy Glencross**

- o Toni is now the Principle Investigator for both the CDC and HRSA grants.
- o Ellie is continuing with the program in a consultative role and will not only serve to provide historical information to the program but will keeping up to date with current activities.
- o Debra Thompson has resigned her position in Newborn Bloodspot Screening.
- o Betsy has already visited 7 of the 33 birthing sites. She is also going to others, further away first, beginning next week. Also stopping at Audiological facilities that evaluate babies. Already seeing some positive results from visits at sites that have not been visited since the program began.
  - Discussed counseling with families following PASS/REFER.
    - ♦ Some facilities make the referral directly; some have the primary care provider make the follow-up appointment.
    - ♦ Many places trying to have REFER come back within 2 weeks for a re-screen before REFER to Audiologist. (i.e. 2-stage screen due to REFER could be fluid)
    - ♦ Louise recommended training for consistency of how results are delivered at the birthing facility.
      - Perhaps a list of definite information that should be included with REFER or PASS.
  - Discussed birthing center follow-up procedures.
  - Eileen mentioned that also need to make families aware that PASS at birth does not mean No loss forever.

- Betsy said the perinatal nurse managers meet quarterly so perhaps she could meet with them to provide information.
- Louise: Mentioned idea of interacting with baby is so critical. Need to teach.
- Lisa: Suggested a script to follow/refer to. Also mentioned that the screening in the hospital was a surprise to her; she had not been prepared for this by the Obstetrician.
- Karen: Maybe talk to prenatal classes?
  - ♦ Betsy: Wants to develop a brochure regarding hearing screening to disseminate to OB/GYN offices and prenatal classes.
- o Intention of MNHP to get a regular mailing of all primary care providers regarding every baby screened and what follow-up is needed. Already getting a report from hospital that baby screened and REFER/PASS was the result. (Similar to letters that go for immunizations and blood spot screenings. Working with public health nurses, etc.)
  - Louise Questions: Would they read these letters? Is the thought that we would add the information to letters that are already going out from blood spot letter?
  - Betsy said no so that the results would be separate.
  - Eileen Question: Why send out a letter on each child? Why not provide a professional letter regarding the meaning of REFER and PASS now and over the long term for their parents. What are the physician's responsibilities for follow-up? Is this another task force "opportunity"?
  - Betsy will share the viewpoints discussed; know that there needs to be more done with follow-up. Must be sure that diagnosis is happening and EI provided. Nothing being done right now.
  - Louise recommended that we put on an agenda to discuss optimal best practice follow-up.
- o EPSDT- Early Periodic Screening, Diagnosis & Treatment (deals with MaineCare patients to ensure follow-up for healthcare appointments, etc.). As of July 1<sup>st</sup>, that program will be in with Genetics and CSHN and coordination of follow-up will be addressed.
- o For both task forces and for information, the Board suggested that all members review the website for NCHAM: <http://www.infanthearing.org> to check out the brochures, resources and information already available there
- o Task Force = One group will be established to work on the following:
  - Counseling materials for birthing centers to facilitate information on how to share newborn hearing screening findings.
  - A professional letter regarding the meaning of REFER and PASS now and over the long term for their patients. What are the physician's responsibilities for follow-up?
- o The Ballard House in Portland had stopped performing hearing screenings in January 2006 and had indicated they no longer wanted to provide the service at their facility. Betsy and Toni met with them in May and the decision was that they would do the screening. They will start as soon as their equipment and supplies can be updated and the staff/midwives are trained.

- o CDC/EHDI Grant resubmission report was done in March. No word as of yet. The new fiscal year starts on July 1, 2007.
- o Working on the HRSA grant. It is due on June 18<sup>th</sup>. This new fiscal year starts on September 1, 2007.
- **ECFS**
  - o New referrals tend to be 2-3 years old (meningitis, ect.) Referrals from Audiologist, 1 from CDS-Search.
  - o Still have 2 open position for ECFS consultants (1= 1/2 PIT teacher)
  - o Great Family Literacy Day on Saturday.
  - o Family Learning Day on June 20<sup>th</sup> on Mackworth Island. Gene Olivier keynote speaker.
  - o Still doing communication monitoring.
  - o Doing Communication Plans for al Children serves with actual features described.
    - Monitoring of measurable outcomes/goals is critical.
- **CDS**
  - o Still in “Augusta limbo”
  - o ECFS is working with Dover, Bangor & Waterville regarding how services should be delivered to children. ECFS is drafting a proposal for best practice. CDS wants a co-ECFS+CDS 1<sup>st</sup> visit. CDS wants to always go and it is good for them to hear ECFS information. ECFS feels there is a lot of ECFS work to do and scheduling cannot wait for CDS. If it works with three sites then may bring it to the rest of the CDS sites.
  - o Model of one CDS provider representing all specialties can be devastating. Only one primary goal with provider who works with other professionals.
    - Concerns that the goal cannot be met with provider who does not understand the specific deficit area (including hearing loss).
    - CDS feels just one provider going in is best. ECFS is concerned that the one person may not understand HL, language development with HL, etc.
    - Concern that CDS counsels family that they do not need ECFS.
  - o Eligibility Meetings by CDS using Batelle Developmental Screening, with ECT following and a plan developed quickly without time to think/plan.
    - Can always come back to ECT but it can be hard to gather.
    - Also ECT only has to meet every 12 months.
    - At age 3 if not in a program the provider (SLO) cannot be paid to go into the home.
    - Concerns that hearing loss should be automatically eligible. Should be preventative as know access is an issue and we know that.
  - o Right now at age 3 cannot get any services in the home. If the child is not in a program. They could go to the specialist’s office or no services.
  - o Concern is lack of consistency between CDS sites.
  - o Can be eligible for Part C (service coordination) and Audiology but nothing else.
  - o CDS says that families have the right to choose but we don’t have to provide.

- **hear ME now!**
  - o Searching for a new director and a TOD. Carrie not here today as she is doing interviews. Hopeful for a new director within the next month. Great candidates for both positions.

### **III. Action Items from Previous Meeting:**

- **Audiological Reporting Form**
  - o We have been working on this since 11/16/06 Maine Academy of Audiology meeting. It is close to being done; significant group process with many involved.
- **Parent Materials for dissemination by Audiologist**
  - o All the Flip charts (unilateral, mild hearing, original booklet) that we approved at the last meeting have gone through the approval process, out to bid at printers. Waiting for it to be pushed forward/printed.
- **EHDI Conference**
  - o Not much time for networking although some of the classes were wonderful.
  - o Very well attended and there were 'size of session' issues. Maine did maximize resources by going to different sessions.
  - o Family that was the subject of the documentary "Sound and Fury" presented a Plenary Session. There is a 6-year later documentary available.
  - o Noted a lot to still accomplish from what other states are doing.
  - o Kristen enjoyed sessions on Auditory DysSynchrony and CI
  - o Karen enjoyed the networking. Also discussions recommendations for how to write recommendations for FMs, Communication Plans, etc.
- **Legislative Updates:**
  - o **LD # 1142 – MNHP Bill** ready for enactment
  - o **LD # 1239- Task force Bill**-Formation of a working group therefore it does not have all legislative issues. Need # 7 legislators and funding. If no one objects then it is passes. Betsy thinks it will be automatically passed.
  - o **# 1850 – ("CDS Bill")** – Listed as ought to pass"
  - o **HA for Children Insurance funding Bill**- Anticipated a divided report last week but this morning it was listed as "ought to pass".
- **MNHP Board Membership**
  - o Process is to submit group appointment recommendations with evaluation of board composition and most roles to be filled.
    - Having these seats filled is mandated
  - o Karen Perry has submitted paperwork.
  - o Lisa Glidden here today and interested in being on the board with paperwork submitted.
  - o Katelyn Driscoll, TOD is also submitting paperwork to join.
  - o Harriet Grey, Adult who has CI implanted as an adult, is interested.
  - o Melinda Smith has not responded with resume and letter of interest yet.
    - Romy will follow-up with her.
    - Works at CCC as case manager for children.

- o No applicants for RN, Hospital Rep, Rep of Health Insurance Carriers (general and MaineCare), CDS.
- o Concern for members of Board who do not come to meetings. What do we do?
- o Review of sample letters that are sent to possible members of the MNHP Board
- o Michelle Markie cannot attend on Monday and Wednesday.
- o We need to look at flexing the schedule for meeting after 2007. Will look at schedule for days of week at the Fall meeting for 2008.
- o Review of letter to potential members.
- o Moving member's around- people who could move into other categories.
  - There is a list of members and other slots that we could fit into.
- o Can have more than the list of must have positions. Can be a number of "others".
  - Eileen comment that must have the professionals on board.

#### **IV. New Agenda Items**

- **Advisory Board Guidelines and Elections**
  - o Rules and Laws in packet that was mailed to members prior to meeting. They were most recently updated 1/4/05 and need update due to terminology changes.
  - o "HOMEWORK" – All review to change certain items. Ex. Maine Department of Health. Wording is not correct. If there are other changes the Board wishes to make, this is a good time to do it. We will take up this issue at the September meeting.
  - o Elections are supposed to be on a yearly basis. Need a quorum. We haven't voted in a while- plan for Fall.
- **Specialty Providers-** Romy reported from last Friday's sub-committee meeting
  - o Letter edited for providers for our list of professionals trained in birth to five with specialists trained in hearing loss.
  - o Combined some categories (i.e. SLP & AVT)
  - o Too many professionals to mail to so will distribute via professional websites, etc.
  - o We will develop materials for MNHP to add to their website.
    - It will be an open list. Not endorsing so anyone who wants to link can do so.
    - Professional training being researched
    - Evaluating the SHINE surveys to make our surveys and results searchable and reader friendly.
- **Updated Audiology Provider's List**
  - o Done and waiting for it to come from the printers.
  - o Some new facilities in the Category A (Full Diagnostics) – from #5 to #7
    - (Added Goodall and a Portsmouth NH practice that sees Maine babies in Stratham @ Professional Audiology Center)

- **Updated High Risk Indicators**
  - o Provided to Birthing Facilities to help with data management and tracking to ensure tested every 6 months until age 3 years.
  - o Noted? Error = Pre not post auricular tags.
- **Audiologist Consulting Position to Maine Newborn Hearing Program**
  - o Kathryn Girardin's contract ends 08/31/07. She will not be renewing her contract.
  - o An RFP is being written so anyone interested who qualifies can apply (this allows a general advertisement for the position). By doing this, the State process is involved and Toni and Betsy will not be the final decision makers.
    - Can only say what is required of the person who will hold this position.
    - Toni and Betsy may not know who applies.
    - Betsy will let us know when the RFP is advertised – probably in July.
    - The contract is set for a specific dollar amount and with a number of tasks to be performed listed. Qualifications listed are minimum and desirable.
      - ♦ Examples include: Interpretation of Audiology findings for database, Review of materials, Providing training
    - The Audiology Consultant is welcome at the MNHP Board meetings but not a voting member
- **Parent Support Part-Time Position**
  - o Being contracted with MECDHH/ECFS
  - o Follow-up work will be done this summer with families who have not had follow-up
  - o In the upcoming budget year, the parent will do some consulting with families in addition to loss-to-follow-up, and starting a Parent-to Parent Chapter for Maine, and Guide-by-your-Side Program.

**V. Future Meeting Dates:**

- **Wednesday, September 26**
  - o Please note we will be holding elections and reviewing rules/guidelines at this meeting as well as welcoming newly appointed Board members.
  - o We will also be planning for the upcoming year with meeting dates, speakers and agenda items.
- **Monday, December 3**